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ABSTRACT

From July 30-August 1, 1998, eighty parents and family members from across the country attended a national workshop held in St. Louis, Missouri sponsored by the National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind and the National Family Association for Deaf-Blind. The workshop, entitled "Going for the Best: Building Excellence and Strength Together," was held in order to generate a list of the most important practices to parents of deaf-blind children of all ethnic backgrounds and ranging in age from infant to young adulthood, in the areas of communication, behavioral issues, and instructional strategies in the education. This brief booklet lists the most important practices indicated by the parents who attended this workshop. The booklet lists 10 strategies each for the areas of communication, positive behavior management, and instruction and program development. Also listed are five strategies for family and social support. Examples of the included strategies are: (1) Each individual who is deaf-blind should be provided a communication facilitator; (2) training should be provided to ensure that a variety of people are able to communicate with the child; (3) all deaf-blind youth and young adults need to be trained in self-advocacy and leadership; (4) service providers and others should know appropriate, current, and positive behavior strategies and supports; (5) a range of housing, supported living, supported and independent work, community, recreation and social options should be available; (6) continued and non-interrupted services needed throughout the life of the deaf-blind individual are needed; and (7) networking opportunities should be provided for families. (DB)

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PARENT PERSPECTIVES ON...

COMMUNICATION, BEHAVIORAL, AND INSTRUCTIONAL STRATEGIES FOR CHILDREN AND YOUTH WHO ARE DEAF-BLIND

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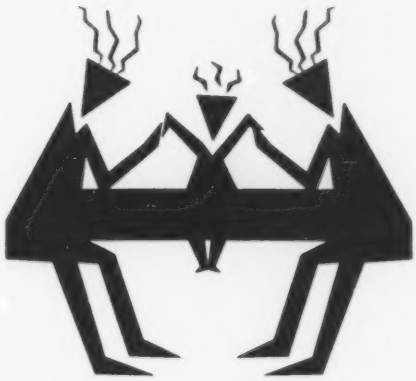

From the 1998 National Parent Workshop sponsored by:

The National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC)

The National Family Association for Deaf-Blind (NFADB)

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INTRODUCTION

From July 30 - August 1, 1998, eighty parents and family members from across the country attended the national workshop "Going for the Best: Building Excellence and Strength Together" in St. Louis, Missouri. The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC) and the National Family Association for Deaf-Blind (NFADB) sponsored this workshop.

The children of these eighty parents represented the full diversity found within the deaf-blind population, as well as an age-range from infant to young adulthood.

The goal of the workshop was to generate a list of the most important practices to parents in the areas of communication, behavioral issues, and instructional strategies in the education of their child who is deaf-blind.

What follows is a list of those practices.

Parent Perspectives on...

Important Practices in Communication

1. Families and professionals need to gain an understanding of various communication techniques, strategies and modes in order to give the child an individualized and appropriate communication system that reflects the child's assessed needs and respects the family's choice. Children should be provided with multiple communication approaches including total communication, sign language, pictures and augmentative communication methods in both home and school environments.

2. Teachers and service providers must understand that all behavior has a communicative function and should not be a "problem." Individuals who are deaf-blind should have the opportunity to express their needs and frustrations without being judged.

3. Each individual who is deaf-blind should be provided a communication facilitator (certified interpreter, trained intervenor, teacher assistant, etc).

4. Training should be provided to ensure that a variety of people are able to communicate with the child.

5. Children and adults who are deaf-blind should be given the right to communicate and be "listened to" with adequate time to respond.

Parent Perspectives on...

Important Practices in Communication, continued

6. Children and adults who are deaf-blind should be provided with the necessary tools to encourage acceptance into his or her preferred community (i.e. deaf community or other appropriate communities).

7. Individuals who are deaf-blind should be provided the opportunities to succeed, take risks and even fail.

8. American Sign Language should be offered as a foreign/second language in school and community settings.

9. Community and businesses should provide access to communication (in a variety of modalities).

10. Professionals and paraprofessionals should be appropriately trained and required to maintain high standards of practice.

Parent Perspectives on...

Important Practices In Positive Behavior Strategies

1. Behavior is a communicative function which must be understood and acknowledged as communication.

2. Individuals with deaf-blindness have unique needs that must be met. Their individual likes, dislikes and personality must be respected.

3. All service providers, including those in the mental health field, need comprehensive training about the uniqueness of deaf-blindness and its impact on behavior. A range of services must also be available.

4. All persons who interact with the deaf-blind individual must understand the impact of deaf-blindness on life.

5. All deaf-blind youth and young adults need to be prepared and trained in self-advocacy and leadership.

6. All parents of deaf-blind children need networking opportunities to share information on behavioral issues in order to learn new ideas & strategies.

7. Service providers and others should know appropriate, current, and positive behavior strategies and supports.

8. It is important to provide the individual who is deaf-blind with a sense of security, affection, love and patience.

Parent Perspectives on...

Important Practices In Positive Behavior Strategies, continued

9. Encourage self-advocacy from an early age, focusing on the person first, not the disability.

10. Members of a team and other service providers working with the individual who is deaf-blind must understand that medical issues/medication can impact behavior.

Parent Perspectives on...

Important Practices in Instructional Strategies and Program Development

1. A range of housing, supported living, supported and independent work, community, recreation and social options should be available.

2. Expectations for the child should not be underestimated. Give the child opportunities to succeed, take risks and even fail in an environment of security, affection, and love. Focus instruction on the strengths of the individual with expectations for success.

3. Provide activities that are age appropriate and meet the child's needs.

4. Parents should be provided with training which enables them to be advocates for their child (i.e., teaching strategies, futures planning, legislation, how to understand the planning process, etc.)

5. Families and service providers need to be able to teach advocacy skills to the child. The process should continue over a lifetime.

6. It is important for the individual who is deaf-blind to have a place in his or her community with access to a full spectrum of life experiences.

7. There should be increased community awareness and choices for persons who are deaf-blind (i.e. social opportunities).

Parent Perspectives on...

Important Practices in Instructional Strategies and Program Development, continued

8. Provisions for a continuum of life long services. Provide continued and non-interrupted services needed throughout the life of the deaf-blind individual.

9. It is important for local and state community services to be mandated and funded for deaf-blind youth and adults.

10. The deaf-blind individual must be a valued member of a community that affords him or her a full spectrum of accessible life experiences.

Other Considerations...

Family/Social Support

1. Providers should team with parents to identify, obtain, and provide services (i.e. educational, medical, social, community, and transportation).

2. Families should identify their needs and obtain assistance to identify resources to meet those needs.

3. Families should be provided with continuing training/technical assistance.

4. Networking opportunities should be provided for families.

5. Families and community providers should work together to ensure smooth transitions.

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